

data analysis and the paper. D.B. contributed to the study design, discussed emerging ideas, and contributed to the paper. A.S. and K.M. will act as guarantors for the paper.

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## COMMENTARY

### Don't blame the patients

It is estimated that about 70,000 Americans have sickle cell disease. In a given year, only about 50% of this group will have even one episode of pain. Only between 1% and 3% will have six or more painful episodes, and a minority of patients seem to have severe pain almost constantly.

It is the minority of sickle cell patients who have frequent episodes of pain or nearly continuous pain who repeatedly seek treatment for their pain at hospital emergency departments and inpatient wards. They are difficult patients: they do not really get better, they keep coming back with the same problems, they are demanding, and worst of all, they want narcotic analgesics, drugs that physicians are uncomfortable about dispensing.

Because they engender such discomfort in their caregivers, these patients are generally not treated well. There is little evidence to the contrary; the literature is replete with articles describing, from the patient's viewpoint, inadequate treatment of pain, hostility, and implicit or explicit accusations that drug addiction rather than "real

pain" was their problem. The patients interviewed by Maxwell and colleagues confirm this information.

The clinical spectrum of disease in sickle cell patients ranges from those with severe symptomatic hemolytic anemia and frequent crises to those who would remain undiagnosed but for routine testing. Although it is clear that a spectrum exists in the objective manifestations of sickle cell disease, such as extreme variations in the severity of anemia, aseptic necrosis of bone, and renal disease, we are uncomfortable that such variations in a "subjective" symptom such as pain should also be attributed to the disease. Because there is no demonstrable reason why one patient should have more pain than another and no way to demonstrate objectively that a patient actually has pain, physicians trying to understand the situation resort to a strategy of "blaming the victim." The entire difficult, frustrating situation can be explained by deciding that the patient is an addict and the (otherwise inexplicable) behavior is not due to pain.

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Maxwell and colleagues compare two groups of sickle cell patients: a group that is seldom hospitalized for pain control and a second group that is hospitalized frequently. They try to discount the notion of a biological/medical explanation for this difference in behavior (more on that later) and look for sociocultural factors that might influence how these people manage their pain. In this attempt, they have not collected data on the social factors that might influence the patients' ability to manage their own care, such as income level, employment status, family structure, family support, or relationship with a primary care physician. Instead, they concentrate on coping strategies.

The authors report findings that sickle cell patients who are seldom hospitalized are "sophisticated" and display that admirable quality, a "strong sense of self-responsibility." Those who were frequently hospitalized have followed "the path of least resistance," which leads to "hospital dependency." The former are characterized by "assertiveness," the latter by the extremes of either "aggression" or "passivity." The terms chosen to describe the groups have strongly positive and negative connotations.

Patients hospitalized frequently for episodes of pain represent a difficult and complex clinical problem, which cannot be addressed by exhorting them to be more like their less troublesome peers. Their episodes of severe pain must be managed aggressively. Patients who have chronic pain must receive adequate treatment for pain, with daily narcotics as needed. Their psychiatric problems, including that of drug dependence when present, must be addressed, preferably with the help of a psychiatrist. They must have access to specialists for management of their frequent orthopedic, ocular, infectious, and renal problems. It may take a village to raise a child, but it certainly requires a well-coordinated team, with adequate support, to care for a patient with severe sickle cell disease.

The single most adaptive strategy described among frequently hospitalized patients is the attempt to develop long-term relationships with caregivers. Patients who need narcotic medications, must, if they are to manage their

pain outside the hospital, have a physician who can help them do so and is willing to prescribe an adequate oral regimen of narcotics. It is nearly impossible for most of these patients to find such a physician: most are underinsured, most have difficulty with transportation because of poverty and physical handicaps, and many are socially disorganized as a result of poverty, chronic illness, and hopelessness. Many also have developed, as Maxwell et al point out, an aggressive (assertive) stance toward physicians and other caregivers.

When one adds to this mix the pervasive paranoia about narcotics, which leads to the reluctance of most physicians to prescribe significant doses of narcotics on a long-term basis to patients who do not have cancer, the problem is insurmountable. Patients are reduced to using emergency departments and inpatient hospital stays for pain management.

The authors acknowledge that our systems of social services and of medical care serve these patients poorly; needs for education, housing, transportation and dependable consistent primary care are not met. In spite of this acknowledgment, they have attempted to, and apparently believe they have succeeded in, identifying "responses to health services" among the seldom hospitalized that are adaptive and that, by implication, others would do well to emulate.

I believe they err in failing to acknowledge the most obvious possibility: that those who use the hospital for pain management do so because they have more severe pain, more often. Their own data show that the "frequently hospitalized" had many more pain episodes than the "seldom hospitalized."

It is also an error to look within the patients for correctable causes of "hospital dependency" without examining the obvious psychosocial influences, which might affect the choice to use the hospital. By examining the patients' "coping strategies" rather than their living conditions, we are looking for the pathology in the wrong place. To paraphrase Pogo, the enemy is not the patients, it is us.

## capsule

**Add water for weight loss** Such is the exquisite precision of the body's appostat—which links energy requirements and satiety—that very small excesses in caloric intakes on a regular basis will result in considerable weight gain over time (*American Journal of Clinical Nutrition* 1999;70:448-455). Reducing the energy density of food by adding extra water during its preparation seems to be effective in enhancing its satiating effects: eat soup for lunch.